

Hamilton and Niagara Region Community Gathering

Introduction

People from Hamilton, Haldimand-Norfolk and Brant attended a gathering to explore the concept and practice of Independent Facilitation, with the desire to develop community capacity to deliver this alternative service relationship.

The group of 18 people consisted of family members, and staff from a range of service agencies in the area. Members attended from:

- Hamilton Family Network
- Rygiel Homes
- Community Living Access
- Community Living Brant
- Salvation Army Lawson Ministries
- St. Joseph's Healthcare Hamilton
- Hamilton-Wentworth District School Board
- Hatts Off! Group & Foster homes

Some of the participants were aware of Independent Facilitation through "Building A New Story - Facilitation Leadership Group Training" offered by John Lord (johnlord.net). Two participants who have attended John Lord's training have begun offering Independent Facilitation services with families accessing resources through the Passport Person Directed Planning offering.

What Is Inspiring Independent Facilitation Now?

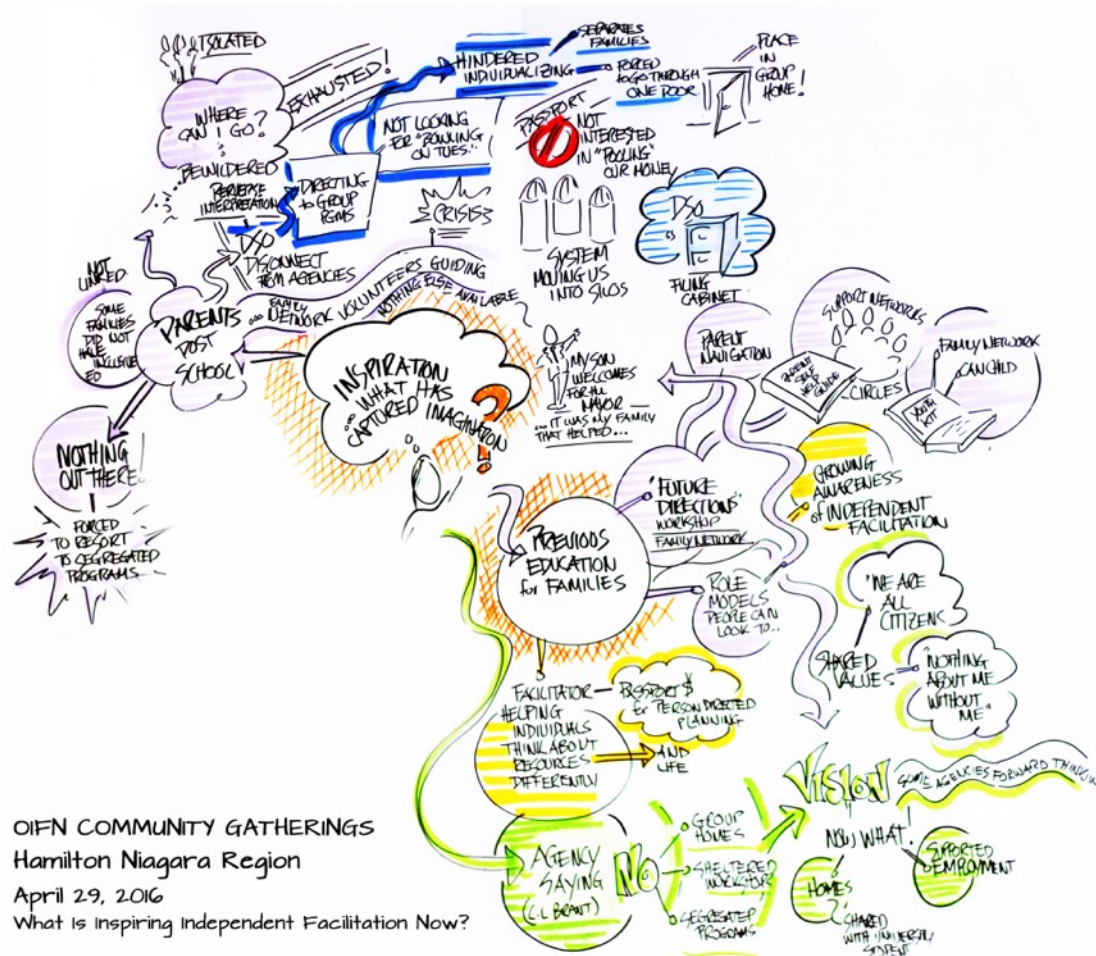
Participants were asked to consider what is happening now in the region that is inspiring the desire to see Independent Facilitation as an option for people and their families.

A DISTURBING CURRENT REALITY...

Parents present articulated a very disturbing reality that occurs for families when sons and daughters finish school.

For those families who have worked hard to see their children included in school and community life, they find themselves bewildered and frustrated:

- exhausted from the hard work involved with keeping their children connected and involved in education and community for 21 years
- as they look for “where can I go?” for support to figure out what life can look like for their sons and daughters after their life in school, they are forced to connect to support and services through the DSO system, which decides what’s best for families, and where they experience:
- being actively prevented from connecting with services directly to seek solutions that are consistent with their priorities of choice, control, citizenship, and community
- receiving information that is inadequate, incorrect, “perverse”, and regressive, sending people back in history to a time



where people with disabilities were segregated and isolated

- being directed to segregated and congregated programs that have “spaces” — group homes, day programs, recreational programs
- no options for individualizing
- under the new ‘bottom line’ people don’t know where they can go for help, a feeling of huge crisis in the community where there is nothing in the community to help parents
- directed to consider “pooling their Passport dollars” with other families to create mini-congregated supports for day and recreation options
- over years of changes in funding and programs, many have ended up in silos that separate families. Families are feeling isolated as the siloed system and ‘privacy’ focus of the DSO makes it hard to connect with other families
- one parent described having to call the DSO in search of support solutions: “it is almost as if I can hear a file cabinet drawer close as they listen and dump my request into a file that goes no where”.

For families who have never had an inclusive school or community experience, they do not know where to begin looking when school is over. After having school as place where their child could go for 30-40 hours each week, they find that there is “nothing out there”. It is devastating to feel that there are no options that can educate them, give them hope for the long journey that lays ahead, or provide real tangible practical support that is desperately needed. One parent described that she was forced to choose a group home because she had to work, and her child needed somewhere to live and be supported. She never would have chosen this, but it was the only solution available. Other families could not even find that option available.

One parent expressed that minimally, the design and operation of the DSO system is irresponsible, and bordering on “criminal” — for the Ontario government to invest millions upon millions of dollars of tax payer money on a DSO system that is regressive, sending people back to a time that segregated and isolated people with disabilities and their families, all under the umbrella of something called the “Social Inclusion Act”. “The money government is spending to support a system that actually damages people and families is a system that is actually working at odds with itself.” The piece that gets lost is open planning and communication as a community rather than a service user.

This is the backdrop that desperately cries out for “different” individualized solutions that can lead to social and community inclusion, full citizenship, and the opportunity for people with disabilities to make contributions to community relationships, and be recognized as valued members who belong.

HOPEFUL SIGNS AND INITIATIVES...

In the absence of anything that feels hopeful and useful being offered by a system that forces people through the narrow DSO doorway, the Hamilton Family Network has developed their own methods of planning and supporting one another to imagine solutions that truly hold as paramount the values of social inclusion, community participation, and belonging. But they do this entirely in a volunteer capacity without any assistance, at a time in their lives when they are weary and exhausted from continually having to battle the structures and forces within government, education, and social systems that are determined to prejudicially isolate and segregate the people they love: “we are volunteers and parents struggling to make this happen”

The Hamilton Family Network has:

- created a “Future Directions Workshop” that brings families together to learn how to develop plans for their sons and daughters that they can implement in spite of a dysfunctional and unhelpful DSO system
- networked families to mutually support each other in navigating the system
- published a Parent Self-Help Guide for developing personal support networks
- developed a “Youth Kit” available online in collaboration with CAN CHILD
- families in the Network have become “phenomenal role models” whose tenacity, dedication, and hard work leads to solutions and innovations that inspire other families and people with disabilities, such as:
 - a parent who has two children with disabilities finds no real support through the DSO system, but in pursuing a vision of her adult son valued in the community has another family member able to make a connection with the Mayor’s office, where her son now plays a vital role in hosting and welcoming visitors to the Mayor each week

One agency in Brant has declared that it will:

- say NO to segregated residential, day, and recreation programs, no longer making “spaces”, and move to dismantle existing congregated programs
- create a VISION for new models of support that promote and enable community inclusion, real employment, choice, and control

There is a growing awareness of “Independent Facilitation” resulting from training events with people such as, Michael Kendrick and John Lord, hosted by local agencies; and there are some people exploring Independent Facilitation in practice where families have used Passport funding for Person Directed Planning.

This gathering of parents and service providers to explore the possibilities of Independent facilitation in the Hamilton and Niagara Region provided the opportunity to recognize that there are people in the area who could be allies with shared values of:

- citizenship
- social inclusion
- and “nothing about me without me”

Understanding What Independent Facilitation Is In Practice: The Ongoing Journey Across The Gap Between Current Reality And A Desired Future

STORIES THAT EXPLORE WHAT INDEPENDENT FACILITATION IS ABOUT

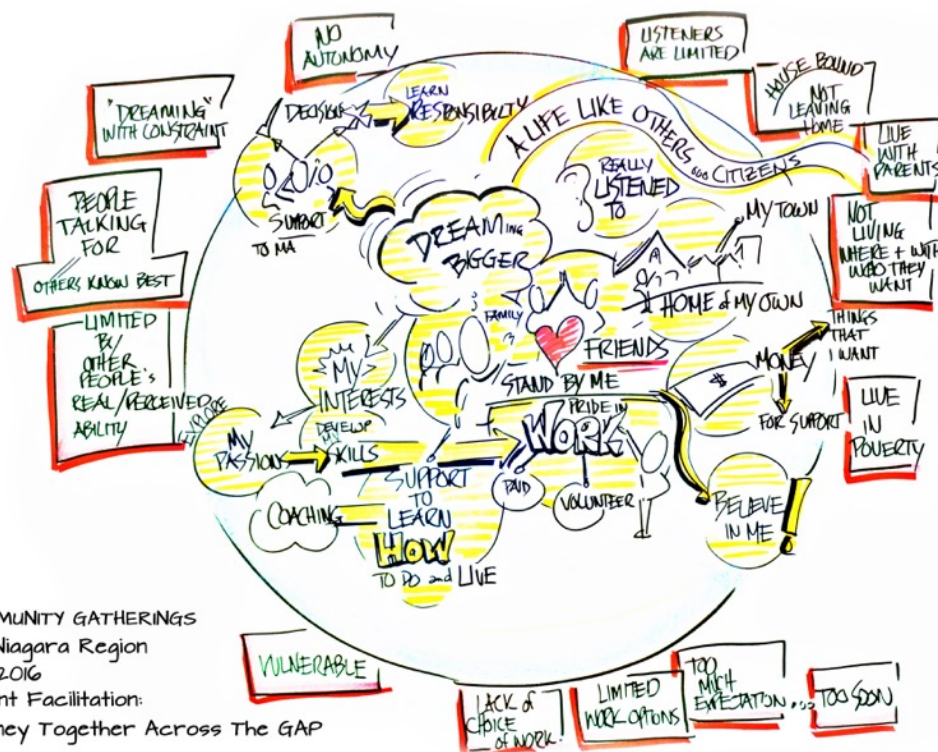
To deepen understanding of the role of Independent Facilitation, the group explored stories.

Participants viewed the video story of Peter Vichy, from the DVD “My Life, My Choice”.

Following the video each participant was invited to:

- think of a person with a disability who they knew well enough to have a sense of a life that would:
 - make them happy
 - engage them
 - provide a sense of purpose
- draw, with pictures and words, a picture that captures this desired life
- in small groups, make room to listen to each other's vision of this life they have drawn
- have a conversation about what they noticed these stories had in common — choose 2 or 3 of these ideas to share with the larger group

In the large group we created a composite image using the common ideas shared in the small groups. We then asked the group to state what current reality is like in relation to these desired future ideas:



Desired Future	Current Reality
Dreaming Bigger...to be supported to think beyond what exists and imagine the kind of life that they would like to move toward. To be able to dream without constraints, and explore what is really important, what motivates, what inspires people. Really listened to...having people in their lives who really listen to them, who find out how they communicate, and take them seriously.	Dreaming with constraint...people are prevented from imagining beyond what currently exists. Limited by other people's perceptions...people in their life, program staff, government staff, family, limit the exploration of possibilities based on their perception of this person's perceived or real abilities People talking "for" them...people experience other people "knowing best", and not allowing or listening to what people have to say about the life they would like to lead Listeners are limited...there are few people, if any who are available to really listen, mostly because they don't feel they can do anything about what they hear. Parents and program staff feel that they are limited in their ability to respond, or they are afraid, so they cannot really listen.
Supported to make decisions...people want to learn how to make decisions, and how to take responsibility for the decisions they make.	No autonomy...the perception of people as "disabled" or "vulnerable" removes the opportunity for choice. Decisions are made by other people.
Friendship, family, and people who will "stand by me"...having genuine, heartfelt, mutual relationships with people who know, value, and care about the person. A place that I call home, where I live with the people I choose, in the community where I want to live...	House bound...due to lack of support, or transportation, people are stuck at home, unable to get out and meet new people. Live with parents...as an adult people are forced to live with their family because there're no other options available. Not living with people they choose...or where they would want to live. Residential living support offers no choice about who you live with. When it is available, people fill "spaces".

Desired Future	Current Reality
Exploring and engaging in “my interests and passions”... encouraged to think about the things they love and enjoy and plan to pursue these things. Develop skills...based on things that people love to do, and are interested in, develop skills that may be useful and valuable to others. Coached to learn how to do and live...being supported to learn how to increase their ability to master a skill or ability that enables them to be more powerful, and capable of direct their own life, contributing to the lives of others, experiencing pride in their accomplishments. People who believe in me...having people who recognize the person’s potential, see how they can bring value, know that they are more than their disabled diagnosis. Experience Pride in work...having the opportunity to know that they have brought value to other people through their commitment, skills and contributions. This can be through paid or volunteer work opportunities.	People are seen to be “vulnerable”...this perception may be based on real conditions, such as health related vulnerabilities, or circumstances, such as not having people they can trust who watch out for them. The end result is that focus and attention is directed to the vulnerability, and not the positive aspirations of the person. People become trapped by their “vulnerability”. Lack of choice and options for work...extremely limited options to be supported to explore real paid or volunteer work options that align with the person’s interests, skills, and ability to make a difference. People either have no choice, or they have choices limited by what exists through existing employment programs. Set up to fail...people run the risk of negative work experiences when they are placed in situations that have too high expectations related to their starting abilities, or the speed that they are expected to master the job is too fast
Money...to live (home, food, clothing), and have the things in life that they desire and are interested in...and money for support that allows people to pursue the life they choose while being safe.	Poverty...people are forced to live in poverty by limited options for exploring work and earning, and a social assistance (ODSP) system that keeps people poor.
To live like other people, as citizens...people would like the opportunity to be seen as citizens and to live like other people do.	

Independent Facilitation is the work of supporting people over time as they move across the gap between current reality, and a desired future where people can be happy, safe, engaged and recognized as valued contributing citizens. It is “Independent”, meaning that it is not attached to or limited by the constraints of the existing service system programs. It involves:

- meeting a person where they are at
- listening to the person - this involves discovering the way that they communicate, and paying action to things like:
 - what is important to them
 - who is important to them
 - what would they imagine for their future
 - what are their gifts, capacities, and contributions
 - what brings them joy and happiness
 - what kind of support do they need
- getting to know their family, and helping the family listen to the person
- learning about their current reality
- facilitating planning for action to move toward a desired future
- support in finding and accessing resources that make it possible to move forward including:
 - funding programs:
 - disability specific
 - other focused (eg. housing)
 - community resources available to all citizens
 - people, places, and groups that can offer participation and/or support

- ...and more
- supporting the person and their family in exploring decisions and the potential consequences and responsibilities that are involved.

Steps to Move Forward...

Time was significantly limited at this gathering to allow for any in depth future planning. While some people were familiar with the concept and practice of Independent Facilitation (largely through training sessions offered by John Lord through local agencies), for others it was a new concept and potential service offering.

At this point, the following steps will be taken:

- a participant email list will be distributed to the group participants to enable connection and information sharing, training and raising awareness
- some local agencies have plans for hosting learning events and training sessions that are relevant to the practice of Independent Facilitation, including:
 - training with John Lord
 - workshops and presentations with Michael Kendrick
- local organizations, such as Community Living Brant, are thinking about how they might act as a “backbone” organization to help foster things in their community, such as gathering people and families to share what they would like with John Lord and Kimberly Gavin
- Voices Unlimited, a strong self-advocate group in Norfolk is contributing to thinking about how to start connecting people again, and how to hear people’s voices again
- participants are encouraged to:
 - Sign up for ongoing notices and information about Independent Facilitation available through the Ontario Independent Facilitation Network, oifn.ca. There is a purple “SIGN UP” button located on the bottom of the home page.
 - Register and attend the OIFN “Common Threads” Conference to be held Nov. 16-17, 2016.

- bursaries may be available for families to participate in the conference



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